

**HEALTH ACCESS FOR VULNERABLE GROUPS:  
A STUDY ON THE “GYPSY” NARIKURAVAR COMMUNITY  
IN TAMIL NADU, INDIA**

By

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## ABSTRACT

The study aims to assess the intersection of gender, education, socio-economic status and nomadism, and its influence on health behaviors and health care access of the “Gypsy” semi-nomadic Narikuravar community in Tamil Nadu, India. The research was conducted through interviewing 51 Narikuravar women, using a semi-structured method. The results revealed that the low education level of women and their semi-nomadism negatively affect their access to information about accessing health services; although the community is open to allopathic treatments, it has a low rate of allopathic care utilization, which they almost never frequent for chronic and non-urgent medical situations; many women are familiar with the concept of health insurance, but the rates of enrollment and utilization are very low; a large part of Narikuravars prefer using private sector care over public sector one; and the community faces stigma and discrimination while accessing health care.

*Keywords: health access, health utilization, discrimination, socioeconomic status, India.*

*Acknowledgement: The interviews were conducted with the help of a team in Chennai, India, led by Saranya Vadhani.*

## I. INTRODUCTION

The current study aims to assess the intersection of gender, education, socio-economic status, discrimination and nomadism, and its influence on health-seeking behavior, health care access and health care utilization of the Narikuravar community. The Narikuravars are a “gypsy”, semi-nomadic community that spills across borders, but mainly live in Tamil Nadu, India. They are known to face discrimination that translates into low education level, low socio-economic status and lack of appropriate access to health care. However, no study had been previously done on the community’s health access and health behaviors.

The research was conducted with Dr. Cristina-Ioana Dragomir by training a team of interviewers and subsequently interviewing 51 Narikuravar women, using a semi-structured questionnaire method. The results revealed that the low education level of women and their semi-nomadism makes it more difficult to access information about health services, and that informal community networks are important means of conveying health information; although the community is renown for using natural treatments, it is open to allopathic treatments, but has a low rate of allopathic care utilization, which it almost never frequents for chronic and non-urgent medical situations; many women are familiar with the concept of health insurance, but the rates of enrollment and utilization are very low because of long waiting time, bureaucracy, lack of information and lack of understanding about how to utilize it; some Narikuravars prefer using the private sector over the public sector despite its large out-of-pocket costs, because of the low quality and discrimination they face in the public sector; the community faces stigma and discrimination while accessing health care; and the Narikuravars are very reliant on government services given their low socio-economic status, which makes rethinking health policy vital for their well-being.

Since “good health and well-being” and “reduced inequalities” (United Nations, 2015) are two main objectives of the United Nations Sustainable Development Goals, providing appropriate and equitable health care access for vulnerable populations is a global priority. This study is informative of the health situation of the Narikuravar population, but more research is needed in order to integrate other vulnerable, “gypsy”, nomadic populations into their respective country’s health care system.

## **II. HEALTHCARE FOR THE BOTTOM OF THE PYRAMID IN TAMIL NADU**

India is renowned in an international context for its numerous challenges, including little government financing, poor health indicators, inadequate healthcare infrastructure and insufficient trained medical staff. India’s spending on health as a percentage of GDP is on the lower side, at 4%, while only 33% of expenses are covered by the government. The social determinants of health are also low compared to similar countries like Bangladesh, Sri Lanka and Thailand, as only 36% of the population has access to sanitation, and the literacy rate is 65%. The health outcomes are also lagging behind similar countries, with 66 years of life expectancy, a 41 per 1,000 infant mortality rate and 190 per 1,000 maternal mortality ratio. The public health spending is focused on preventive care, and particularly vaccination, as well as on a portion of inpatient care (Danzon 2017).

Tamil Nadu displays better average health indicators than India: life expectancy at birth is almost 3 years more at 68.9 years, the infant mortality rate is almost half of that of India at 21 per 1,000, and maternal mortality ratio is lower than half of the Indian average at 90 per 1,000 (Government of Tamil Nadu 2012, 194). Therefore, Tamil Nadu is considered to be one of the

most advanced Indian states in terms of health outcomes. The state's health care system includes a primary health system comprised of Primary Health Centers and Health Sub-Centers, a secondary health system that consists of District Head Quarters Hospitals, Taluk Hospitals, Women and Children Hospitals, Dispensaries, Mobile Hospitals etc., and a tertiary healthcare system that includes multi-specialty hospitals (Government of Tamil Nadu 2012, 198). However, the complex health care system and the good statistical averages of health outcomes do not reflect the situation of marginalized groups that don't have access to health care, because of structural issues, financial problems, socio-cultural mismatches, or stigma and discrimination.

India's large population and its socio-economic differences are reflected in the income distribution: about 200 to 300 million people are considered part of the middle class and the rich, with the rest of more than 1 billion Indian citizens pertaining to the poor class (Danzon 2017). This lower income population is especially affected by potential health shocks, as the expenditures associated with them are one of the major causes of poverty traps in India. Although public health facilities offer services free of cost nation-wide, they are often inaccessible because of their geographical location and low density, insufficient medical staff and health technology, or simply their poor quality. Many therefore seek care through private providers despite the large out-of-pocket cost associated; on average, 40% of the hospitalized patients in India have to borrow money or sell assets to pay for their treatment expenses, which represent around 58% of their annual household expenditures (Burns 2014).

To mitigate some of the risk associated with individual health shocks through risk pooling, a number of public and private stakeholders offer private health insurance. These include the national and state government-sponsored insurance schemes, but also private-sector schemes, microinsurance schemes and other community-based insurance scheme models. However, the

relative high cost of accessing private health insurance is prohibitive for most of the poor, and is designed for the wealthier population that can afford to purchase it.

Thus, to mitigate the risk for the poorest citizens, the Government of India created the national health insurance scheme Rashtriya Swasthya Bima Yojana (RSBY) in 2007, targeting families below the poverty line. This scheme covers catastrophic health events and reimburses hospitalization costs at approved providers, with an annual ceiling of Rs. 30,000 per family (La Forgia 2012, 295). While a large number of Indian states approved the implementation of RSBY, some supplemented it or replaced it completely with their own state insurance schemes. This is the case of Tamil Nadu, which implemented the Chief Minister Kalaignar's Insurance Scheme for Life Saving Treatments in 2009, which was meanwhile upgraded to the Chief Minister's Comprehensive Health Insurance Scheme in 2012. The government-sponsored scheme is available free of charge to families in Tamil Nadu with an annual income under the poverty line of Rs. 72,000, and offers cashless hospitalization, follow-up treatment and other diagnostic procedures in private sector medical facilities, with an annual ceiling of Rs. 100,000-150,000 per family (Government of Tamil Nadu 2017). The scheme covers 1016 procedures, including 23 diagnostic procedures and 113 follow up packages, such as cardiology and cardiothoracic surgery, oncology, urology, neurology and neurosurgery, ophthalmology, plastic surgery, gynecology, gastroenterology etc. (Government of Tamil Nadu 2012, 208). In 2014, the scheme was implemented in 829 hospitals: 142 government hospitals and 687 private ones (Government of Tamil Nadu 2012, 208). In order to apply for the government-sponsored scheme, families need to go to health camps conducted by hospitals, where they need to present a ration card, an income certificate, a smart card for the scheme, obtained from the District Collectorate, and an Aadhar card, a biometric and demographic identification method (Govinfo 2016). While the

scheme is expected to cover all the families under the poverty line in Tamil Nadu, there are still very large gaps in coverage and utilization, oftentimes associated with the most vulnerable populations who lack access to information or the means to obtain the insurance scheme.

### **III. THE NARIKURAVAR COMMUNITY**

One such vulnerable groups that faces challenges while trying to access health care is the Narikuravar community. The Narikuravar is a semi-nomadic tribe, originating from North India, who migrated to South India half a millennium ago, according to the group's oral history. Although they currently spill over state borders, a large part of the population comprised on 8,500 families, or 30,000 individuals, live in Tamil Nadu, and represent less than 0.1% of the state's population. They are identified as a "Gypsy" population, having similar roots and culture as other Romani communities, and at times facing the same type of stigma. Similar to other "Gypsy" groups, the Narikuravars are an understudied population, and so far no formal study has been done about their health status and health access, except for the current one.

Generally recognized as having a low socio-economic level, the Narikuravar struggle with high levels of illiteracy and unemployment, and low access to public services like healthcare. Traditionally, the Narikuravars are hunters, as their name means "fox" or "jackal hunters". However, since hunting was outlawed in India, the group's main occupation became selling home-made beaded jewelry or cheap plastic products at festivals and around temples, with part of the community employed in jobs such as collecting garbage. Given their poverty level and distinct culture, they are oftentimes marginalized and even ignored in day-to-day situations, and their main interaction with the people outside the community is through their small businesses.

There is a stigma associated with talking to the Narikuravars, who are perceived as dirty, “eating cats and dogs”, loud and uneducated. For example, it is highly uncommon that Narikuravars can eat at the same table as people outside of the community (Dragomir forthcoming).

The Narikuravars face institutional marginalization as well. Historically, they were placed under the Criminal Tribes’ Act of 1871, signaling their threat to the Indian society under British rule. They are currently categorized by the government as one of the Most Backward Classes, which makes them part of the Other Backward Classes (OBC) group. However, the community has been fighting for achieving a Scheduled Tribe (ST) status, given their low socio-economic status and tradition as a nomadic group which migrated from North India. OBC communities are comparatively wealthier than ST groups; for example, in Tamil Nadu 31.2% of STs fall below the poverty line, with only 19% OBCs. Therefore, OBCs tend to receive less financial assistance from the government, and have access to less schemes and public services. Achieving ST status would not only allow the Narikuravars to access more government benefits in order to improve their scarce educational, health and employment opportunities, but would also decrease the competition for resources between the Narikuravars and other groups that are more strongly represented in Tamil Nadu (Dragomir 2017).

#### **IV. LITERATURE REVIEW**

Although there has so far not been any research assessing the influence of different social factors, such as socio-economics status, discrimination, gender bias and education, on the access to health care of the Narikuravar community, previous studies on vulnerable or impoverished populations represent a good starting point for creating a theoretical framework. The current



literature conveys the effects of education, gender, poverty and nomadism on healthcare-seeking behavior and access to care in India, finding a strong correlation between them and discussing both causes and their implications.

Previous studies have focused on understanding quantitatively the effect of different social characteristics, particularly the levels of women's education and the family's socio-economic status on health outcomes, with predominantly positive correlations. Mathew (2012, 203–223) undergoes a systematic review of the existing literature on the inequities in childhood vaccination and their social and demographic causes; there are correlations between the level of child vaccination and factors related to the individual (such as gender and birth order), family (such as area of residence, wealth, parental education), demography (religion, caste), and the society (access to health-care, community literacy level) characteristics. Mathew (2012, 203–223) emphasizes that vaccination rates are lower among infants with mothers with no or low literacy, and families where women are not empowered.

According to NFHS-3 data and the UNICEF 2009 report, maternal education showed a statistically significant effect on whether children ever had vaccination, particularly in the cases of no education, incomplete primary education or only primary education, which are associated with low vaccination rates (Mathew 2012, 203–223). Singh and Yadav support the conclusion that the education of both parents was very influential on the vaccination of the children, and more notably, the effect of maternal education on child vaccination is higher than that of paternal education (Singh and Yadav 2000, 1194–1199).

Moreover, there have been studies linking parental education to reduced infant mortality. Maternal level of education is particularly related to the level of infant mortality and general

child health, with more educated mothers having children with a higher nutritional status, and lower morbidity and mortality. Some of the studies that proved this relationship are: Caldwell 1979, 1994; Caldwell & McDonald 1982; Rao et al. 1997; Desai and Alva 1998; Das and Dey 2003; Khasakhala 2003; Kravdal 2004; Gakidou et al. 2010; Papageorgiou and Stoytcheva 2011; Saikia et al. 2013. Other studies have taken the analysis a step further and used data to prove a causal relationship between the maternal level of education and infant mortality: Desai and Alva 1998; NIMS et al. 2012; Papageorgiou and Stoytcheva 2011 (Choudhury 2015, 544–572).

In line with the above-mentioned national studies, there are numerous local and state-wide studies that link higher maternal literacy to higher health seeking behavior and vaccination rates of children, particularly in New Delhi, Goa, West Bengal, Agra and Udaipur (Mathew 2012, 214–215). To the date, has been little reliable research about the Tamil Nadu state.

In addition to the individual maternal education level, a community's cultural and social capital has also been shown to be an important factor leading to health care seeking behavior. A multilevel analysis of data from the 1991 district level Indian Census and the 1994 Human Development Profile Index shows that there is a correlation between the proportion of literate women in a district and the percentage of children fully immunized in the district. The study models the data controlling the effect of the child's own mother education, therefore showing that community level of education is important for children's access to health and complete immunization in rural communities in India (Parashar 2005, 989–1000).

Moreover, a UNICEF 2009 report details the main reasons for no or incomplete vaccination. Firstly, on the demand side, the main reasons were not feeling the need to, not knowing about vaccines, not knowing where to go for immunization, inconvenient timing, fear

of side effects, lack of time, wrong advice from someone, and unaffordability. On the supply side, the issues focused on lack of availability of vaccines, inconvenience of place, absence of medical staff, long waiting time, long geographical distance, and service unavailability (UNICEF 2009, 3). The demand side causes are particularly relevant to the subject, as they reflect various dimensions and social factors that constrain access to vaccination, and on a larger level to health access in general. Moreover, Kriti (2012, 331–339) proposes four possible causes that determine the positive relationship between maternal education and healthcare-seeking behavior leading to childhood immunization, even after controlling for socio-demographic characteristics.: greater human, social and cultural capitals, and more autonomy within the household. Similarly, the pathways through which parental education reduces infant mortality rate have been hypothesized by Choudhury (2015, 544–572) to be: a higher level of education allows the mother to take better care of her children with more knowledge about nutrition, hygiene, caring during sickness times, immunizing etc.; more educated mothers are more empowered, and thus take their children to health facilities; more educated mothers use health care services more often than non-educated mothers; educated mothers have more knowledge about reproductive health, so is more likely to have healthy babies with higher chances of survival; educated parents tend to have better jobs and thus more income; educated parents have access to social capital and a larger network, that can provide them with advice and best health practices; the privileged position of more educated parents commands respect from health providers, leading to their easier access to health services.

Gender disparities are an important factor affecting access to health care. Gender gaps have been highly prevalent in India, which can be noted from the immunization rate by gender: According to the UNICEF (2009, 3–5) survey, the NFHS-3 survey (Mathew 2012, 203–223), Devansenapathy et al. (2016) and Boorah (2004, 1719–1731), boys are likely to be 2 to 5

percentage points more immunized than girls. Moreover, Boorah (2004, 1719–1731) concluded that girls are more likely to be neglected than boys, through an Indian-wide econometric analysis. However, the treatment of girls is closely linked to the level of literacy of mothers: while illiterate mothers engaged in gender discrimination for access to health, literate mothers did not discriminate between genders; the literacy of the father had no effect on reducing gender discrimination.

Birth order is also particularly important when assessing access to health. The NFHS-3 survey has showed declining vaccination with increasing birth order. Therefore, 54.6% of the first born infants are vaccinated, 45.3% of the second or third born, 29.9% of the fourth or fifth, and 18.5% of the sixth or higher (Mathew 2012, 209).

While family factors are important determinants of healthcare seeking behavior, external factors also play a large role. For example, the social status or caste and the geographical location of the community are a vital factors determining access to health. Access is considerably lower for lower castes and communities living in poverty, as well as for rural groups when compared with urban ones. Singh and Yadav (2000, 1194–1199) revealed that the children living in small, tribal villages with illiterate mothers had the lowest vaccination rate of all groups. Moreover, The UNICEF (2009, 3–5) survey reported the decreasing rank of vaccination rates per group to be: upper castes, backwards castes, schedules castes, with the lowest rate for scheduled tribes. From a cause-based approach, Acharya (2017) discusses the concept of unfair exclusion, “the complete exclusion of a group of people from availing some services for caste based reasons”, while the state health care system is meant to provide services to all citizens without discrimination. She therefore identifies access, availability, self-perception and utilization as the key for assessing differences in opportunities.

Moreover, Acharya (2010) conducted ethnographic interviews in Gujarat and Rajasthan to assess the access to health services of Dalit children, one of the Indian backward castes. She concludes that the major structural issues are that Dalit children receive less doctor-patient time and more waiting time in order to see a physician than children of higher castes, and are often treated with derogatory words or not touched by physicians because of their polluting nature. This leads to a preference of being treated by Dalit doctors, who usually don't have access to the most efficient and up-to-date training, treatments and medication.

While caste and social status are institutionally and societally-constructed factors that lead to certain displayed health behaviors and treatments, some of the vulnerable groups have an additional burden: nomadism or semi-nomadism. According to Omar (1992, 307), nomadic populations are overlooked by policy makers, governments, economists and planners all over the world, particularly in Africa, since the more difficult logistics of delivering health care to these population is viewed as an impediment. Similarly, Sheikh, Mahmoud and Househ (2015, 92) emphasize that the nomadic communities' refusal to change their lifestyle to a more sedentary one is the root cause of their lack of access to primary health care, and the reason why policy-makers are not giving them the required attention. Moreover, Sachdev's (2012, 73) study on the semi-nomadic tribal populations in Rajasthan reveals their main challenges in accessing care: lack of appropriate infrastructure, lack of accessibility to hospitals and clinics, the discrimination and poor treatment by the public sector medical staff, their reluctance to seek allopathic medical treatment, as well as their inability to afford it. Sachdev (2012, 73) discusses the poor health status of these communities, emphasizing the importance of concrete action directed towards increasing awareness of health services and making health care more accessible to these populations. The poor health status of communities with strong internal ties may be amplified by

genetically-transmitted diseases, given the strong internal ties and high degree of consanguinity; for example, Sony (2016) discusses his work with the Narikuravar community in Tamil Nadu, showing a high incidence of Alkaptonuria, or “black urine”.

Therefore, current literature reveals a strong link between healthcare-seeking behavior and access to care and gender, education, caste and socio-economic status, and nomadism. However, no study has so far assessed these factors within the Narikuravar community.

## **V. THEORETICAL FRAMEWORK AND HYPOTHESIS**

The study builds on the previous scholarship in the field, namely the research done by Oster (2009, 62–76), Pandey and Ladusingh (2015, 879–905), Raj (2011, 618), Mathew (2012, 203–223), Singh and Yadav (2000, 1194–1199), Parashar (2005, 989–1000), Choudhury (2015, 544–572), Kriti (2012, 331–339), and Devasenapathy (2016), looking at the effect of different social factors like gender and class on access to health, health habits and health care utilization. Furthermore, our research adds another central dimension of nomadism, and studies a previously under-researched community, as it is the first study focused on the health access of the Narikuravars. Since the study was conducted using a semi-structured interview methodology, with a number of open-ended questions, it didn’t rely on a singular specific hypothesis. However, the goal of the study is to identify specific root causes and pathways through which the community might face injustices while accessing health care, and provide specific, deep insight into the intersection of gender, education, income level, social class and semi-nomadism on healthcare habits, starting from the premise that these are core factors restricting the access to health of the Narikuravar community.

## **VI. METHODOLOGY**

The study was conducted with Dr. Cristina-Ioana Dragomir, a CASI Visiting Fellow at the University of Pennsylvania who has been working with a Narikuravar community close to the city of Coimbatore, Tamil Nadu, for 4 years. In January 2017, the authors traveled to Chennai, Tamil Nadu and conducted field visits and interviews in the main places where the Narikuravars engage in business. The interview questions were developed together with leaders of the Narikuravar community, based on the interview methodologies of other academic literature that links health to education, gender, socio-economic class and nomadism, as addressed in the Literature Review section. A team of local researchers from the Anna University in Chennai were trained to further lead interviews, according to the Helsinki research accord.

The study employed qualitative, ethnographic means of data collection, with a semi-structured interview method, in order to maintain the focus of a classic ethnographic data collection, yet reveal personal experiences that can clarify the specific instances of access to health or lack thereof. The interviews were conducted with women above 18 years old from the Narikuravar community, both from an urban and a rural setting, close to the city of Chennai in Tamil Nadu. The interviewers traveled to the community's settlements or work places, and the interviews took place in public spaces.

The interview was comprised of a structured, demographic data collection part, where interviewees talked about their employment, family situation and education, followed by an open-ended part surveying health behaviors. More specifically, the 93 interview questions assessed the Narikuravars' access to and usage of health insurance, vaccination history, use of

allopathic and alternative medical establishments, focusing on detailing the experiences within hospital and clinics. The questions were translated and administered in Tamil, the official state language.

## **VII. CHALLENGES**

The process of conducting interviews was challenging for various reasons. Firstly, the community exhibits very strong internal ties, so it is difficult to gain their trust as an outsider and thus have the community share personal stories about health experiences. To gain access to the Narikuravar group, the study worked with representatives from the community; however, they faced other challenges. For example, their community members assumed that they already knew the answers for some of the questions, resulting in potentially less specific responses. Moreover, given the comparatively higher socio-economic status of the Narikuravar representatives, who are part of an aspiring middle class, there was mistrust from the poorer Narikuravars. Another level of conflict was based on gender; since some of the interviewers were men, they needed to create a level of trust with the women interviewees, yet not overstep their boundaries, in order to make them feel comfortable sharing their medical history and experiences, which can be highly gender-biased, such as giving birth. While it was preferred to work with female interviewers in order to make the interviewees more comfortable, the low level of education of women who had access to the community was prohibitive.

Another data collection challenge is posed by the semi-nomadic character of the Narikuravars, who travel every day for work, and oftentimes leave their settlements without prior notice. Their unpredictable schedule made it considerably difficult to schedule any interviews in



advance, making the establishment of an interview collection timeline problematic. Moreover, the mobile character was amplified during festivals such as Pongal, the harvest festival, when the community was traveling for multiple days.

Language barriers were also a factor that needed to be taken into consideration. Although the interviewers standardized the translation of the questionnaire from English to Tamil, some Narikuravars face challenges in understanding the language, since their first language is Vagriboli. The local interviewers played an important role in translating certain words in Vagriboli during the interviews. The lack of understanding was amplified by the low level of education of the women interviewed, who were sometimes not familiar with terms such as “health insurance”. Other times, the women interviewed were unable to provide a reliable age for themselves or their children. However, it is important to note that efforts were made to diversify the level education of the women interviewed; however, given the low education in the community, it was very difficult to find highly educated Narikuravar women.

Finally, the social and political context was also challenging at times. Riots that took place during our study in Chennai prohibited the mobility of interviewers for a significant period of time. Moreover, frequent energy cuts and the low access to quality internet and other technology led to data transmission issues and delays.

Therefore, a lot of flexibility was necessary during the interviewing process, in order to accommodate the lengthy process of data collection (e.g. by traveling to find the community) and overcome the structural and technological challenges mentioned above.

## VIII. RESULTS

The study addresses an intersection of multiple topics, through questions that are either topic-specific or cross-sectional. The results are presented through discussion on 10 different categories. Out of them, 5 reflect the main factors and community traits that influence health-seeking behavior and health access: education, socio-economic status, gender differences, nomadism and Narikuravar identity and discrimination. The other 5 discuss the community's preferences for care, its displayed health-seeking behavior, its access to and utilization of care: alternative medicine use, health awareness and use of public services, access to health insurance, experiences in the allopathic system, and health affordability.

### a. Education

The sample of 51 women interviewed showed patterns consistent with the ones known about the Narikuravar community. We notice a low educational attainment: 18 interviewed women never attended school, and only one went to school up to 12 standards, one had a Bachelor's degree and one had a Master's degree. However, the educational results of women were not different than those reported for the men in the family, signaling an overall lack of educational opportunity within the community, rather than a gender issue. Moreover, there is a clear generational divide, with younger women being more educated than older women, and with a majority of children receiving more education than their parents did. One mother we interviewed, Minima, reflected on the importance of educating her children:

I do not know to read and write in any language. I do not want my children to get spoiled like me that's why I sent my children to school. So that children will explain us what is there in newspaper and television. [...] If we stay in home means we can take care of

them well but we go various places for business and take children along with us. We can't earn our bread if we stay in home, and we have left no choice. Due to travel, our children's education gets spoiled. Now also I invested lot in business for the festival by lending money from my cousin. I left my son in hostel and came here for business. (Minima, 30)

Minima's experience shows how Narikuravars' semi-nomadic lifestyle oftentimes impedes children's education, as they cannot be left alone in school as their parents are traveling. Although children education levels are higher than those of their parents, structural issues related to nomadism and poverty ("we can't earn our bread if we stay in home") still force them out of school. Moreover, Minima emphasizes the difficulty of not understanding information transmitted through mass media channels such as newspaper and television as a main reason for wanting to educate her children.

The study revealed that the community speaks and understands Vagriboli, the traditional Narikuravar language, and Tamil, the official state language. However, according to our interviewers, the community only communicates in informal Tamil, and has limited knowledge of formal terms. This makes it difficult to access and transmit information, relying on word of mouth, and sometimes radio and television. Oftentimes, this is more challenging than it seems for uneducated women like Minima, since information about health care can be transmitted in formal Tamil, English or Hindi, which the community doesn't speak. Access to information is also vital for maintaining health and accessing health care:

Only educated people in our community will access hospitals, others will go to medical shops and take medicine, whatever the shop keeper gives. They do not know much about

it, they believe that medical shopkeeper is doctor and medicine that he gives will work well. (Velakani, 20)

According to the quote above, Velakani observed that health care seeking behaviors in the community are associated with a higher level of education, which creates awareness about health services and the benefits of allopathic health over getting over-the-counter medicine at “medical shops”. Moreover, being illiterate makes it difficult to access health care because of the inability to understand the treatment procedures, or even because of not being able to sign one’s name. As Jayalalitha recalls about her daughter being critically ill in hospital,

Then I immediately taken my daughter to Dhanalkshmi private hospital, [where] they refused to give treatment without my signature. They said it is complicated cases to handle hence they need assurance signature to undergo further treatment. I was helpless. I don’t know to read and write, don’t know what was written in the paper. They told me that it is in my hands to save my daughter life. I cried a lot and finally signed for further treatment. (Jayalalitha, 40)

Jayalalitha was thus not able to read or understand the medical procedures that were critical for her daughter’s life. This put her in the position to have to be fully entrusting in the medical staff, which was more knowledgeable. Therefore, low levels of education or literacy can make the members of the Narikuravar community especially vulnerable while accessing health care: their agency during the decision-making process can be reduced to minimal levels, and even manipulated, as their only choice is to blindly trust the physicians.

Discrimination against the community is sometimes a main factor for the lack of access to education:

Sometimes people may insult us. Teachers might scold us mentioning our caste names especially. So at that moment, in front of 30 to 40 students, we people will suffer mentally. Due to this, we don't move forward towards studies. And we feel bad when we were matured enough. Later we come to know about how people are considering us and [how] they insult us because of our nature of work. (Maarthal, 28)

As Maarthal depicts, discrimination based on belonging to the Narikuravar community is still very prevalent in schools, both because of teachers and other students. This has a strong negative effect especially on young Narikuravar children, and the widespread stigma oftentimes leads to them dropping out of school at an early age.

This process of stigma leading to low education attainment becomes particularly problematic in the context in which education is highly correlated with good health behaviors, health-seeking, being able to understand and access health care, and having agency while undergoing medical procedures, as discussed in this section.

#### **b. Socio-Economic Status**

The Narikuravars are known to be in a low economic stratum, which is supported by the findings in our study. Almost all the women we interviewed reported that they are self-employed and sell beaded jewelry, making Rs. 100 to 300 every day. However, we have found a lack of understanding of how to properly calculate profit, and thus daily or monthly income, having basic or no knowledge of personal finance or accounting: “We do not earn or save for annual. We earn and spend daily. We earn around 100 to 200 Rs. per day.” (Pushpa, 22) Therefore, for self-employed members of the community it is difficult to accurately estimate their income, as

they would need to deduct the costs of goods sold from their total earnings. This is particularly challenging given their low education level and limited mathematical skills.

However, it is safe to estimate that a majority of the community falls under the poverty line, set at Rs. 72,000 by the Indian and Tamil governments. Therefore, the Narikuravar community is eligible for government assistance, including the government-sponsored health schemes such as the Chief Minister's Comprehensive Health Insurance Scheme. However, since self-employed workers do not report taxes to the government and do not keep track of their yearly personal and family income, it is difficult to prove their belonging in this poverty income bracket. These bureaucratic issues may further prevent the community from accessing government assistance programs that they are entitled to.

### **c. Gender Differences**

While pertaining to a low socio-economic class has been proven to be related to more gender disparities, gender relationships within the Narikuravar community showcase an intersection between traditional values and need-based modernity in India. Narikuravar women often have multiple daily roles, including taking care of the children, doing housework, and bringing income to the family through being formally or self-employed. Their central role in the economy of the household stands out from other scenarios in India, as they are able to have more autonomy and arguably a larger role than men in family life. This is reflected in the community standards, where women are allowed to represent themselves in the community socio-political life by being leaders of women's groups.

Moreover, the answers also indicate the gender preferences of women and their families. India is known for having one of the lowest sex ratios of females to males, due to cultural

discrimination against women. According to the 2011 Indian census, the average gender ratio is 940 females to 1,000 males. However, the South part of India shows more equal sex ratios, with Tamil Nadu being the third most equal Indian state after Kerala and Puducherry, with 987 females per 1,000 males (Government of India, 2011). Interestingly, our data shows that a large majority of women in the Narikuravar community and their families don't have any preference for their children's gender, stating that they were "hoping to have healthy and good child" (Savithri, 48). Moreover, none of the women we interviewed had done any prenatal test to find the gender of their child; although this practice is prohibited in India due to the large abortion rates by gender, it is the main mechanism of fetus selection by gender. However, there were exceptions where the husband insisted on the importance on having a son:

No I didn't do any test to find out gender. But they told before because the previous delivery I got female child. So my husband said if the other child is female I will leave you and go. So I asked the doctors and they confirmed that it is a male child. (Radha, 25)

In cases like this, alternative medical knowledge was used instead of scientific prenatal test, as the community believes in identifying the fetus's gender through different pregnancy signs.

However, abortion rate is high in the community. Out of the 46 interviewed women who became pregnant, 21 had at least one abortion, with a majority having more than one. Moreover, 17 of them gave birth to children that faced neonatal or infant death.

I was pregnant for three times. I was forced to abort twice the times by my husband and his family. (Maarthal, 28)

I got pregnant twice. I aborted one child due to family issue as my husband was not ready. At times, abortions are imposed by the husband and his family, demonstrating an unequal gender power dynamic. However, other times abortions are unintentional or intended by the woman herself. The high incidence of abortions and neo-natal deaths within the Nairkuravar community underscores the importance of providing family planning and sex education, as well as providing more access to prenatal, delivery and post-natal care.

Early marriage is also common within the Narikuravar community. This is particularly problematic when the married girls are children who do not have a say in the process, which is arranged by their families. Given the strong internal ties, it is difficult to marry outside of the community. The young age and lack of choice increases the women's economic and social dependency on men, making them more vulnerable. However, all the women interviewed were married, as marriage is a central cultural pillar of the community.

Our community, we girls will get married at 15 or 16 years of age. Once we got married, we are into the hands of our husband. (Maarthal, 28)

I got married when I was an adolescent girl even [though] I didn't attain puberty. So I was not enough matured to understand society and myself at first. Even I didn't even know about my husband, whether he was a gentleman or not. But later I came to know that he was a drunkard, so because of his habit our family is not able to earn a proper and stable income. And also as a contagion, our entire family has got affected from the habit including myself, my daughter and my daughter-in-law. (Rajeswari, 37)



Early female marriage results in the women not being able to have control over their own future, which is “into the hands of our husbands”. Being married at 15 or 16 on average also leads to a lack of ability to pursue education past middle school. Moreover, strict family norms in which the wife becomes part of the husband’s family after marriage subjects her to constraints on her freedom sometimes, if faces with traditional patriarchal rules. Therefore, some women are not allowed outside after dark, and therefore their work autonomy is limited; otherwise, they can be suspected of being unfaithful wives, as Velakani explains:

We face very [many] difficulties, especially [as] women. I have studied but I didn’t go to any work. In my community we have a practice that women will always stay in clan after sunset. So we can work in the morning but not night. Even if we stay in at night we will be with our husband. If we break this and go out, we will be haunted [because of the] suspicion of the husband. Our character will be questioned. So we better stay with family itself. [...] We women do respect our culture and will obey our male family members’ worlds. (Velakani, 20)

Another reason impeding children’s education, beyond marriage, can be related to culture and gender discrimination. As Vanitha (35) remarks, her daughter never attended school; although she wanted to enroll in school as a teenager, she wasn’t allowed to “because she has attained her puberty and it is not allowed in our community to do schooling after attaining an age”. Other women report facing discrimination manifested through violence, coercing them to stop pursuing an education:

No, I did not study, I ran away from the school because I faced racial discrimination and got beatings from teachers for others mistakes. (Mary, 40)

Although the Narikuravar community might seem more focused on gender equality than other poor Indian communities, due to their relative lack of fetal sex selection and the important role women play in the family and community, women still face a multiple-layered burden because of early marriage, poverty and high family responsibilities, relative lack of autonomy and resulting low access to education. Because of these factors, women may need their husbands' approval before accessing health services, and their lack of education makes it more difficult for them to be informed about good health practices, such as family planning and pregnancy check-ups. This may further translate into lower health-seeking behavior, both for themselves and for their families.

#### **d. Nomadism**

The Narikuravars live as a semi-nomadic community: although they have settlements, they travel every day, usually for business, and sometimes they are very difficult to locate. While they use their address to get government benefits, as citizens of Tamil Nadu, they are oftentimes not at their residence to claim them or be able to use the social system provided. Their semi-nomadism often disrupts their children's formal education; to attend school, the Narikuravar children would have to be sent to a hostel during the school week while the parents travel for work. Moreover, if their movement transcends state borders, the Narikuravars are unable to utilize their Tamil-specific health insurance anymore; therefore, this restricts the places in which the community can access health care at low or no cost. Not spending the majority of the time in their settlement also means that the community is more difficult to reach by government workers spreading public information and awareness campaigns, signing them up for free government insurance schemes, or giving them vaccines and nutritional supplements for their children. Siruvalli, 36, explained

why she wasn't able to receive a Family Card, that would entitle her to access government benefits for the poor:

I have raised a request may time but still not getting it [i.e. a Family Card]. We won't available most of the time in home for further verification process. We usually travel to other places for business due to which we are not getting any updates properly and also are not able to access many services. (Siruvalli, 36)

The community's mobility therefore hinders their access to information, which is even further restricted by their low education and literacy rates. The Tamil government has not yet devised methods to keep in contact with this group that is always on the move. Furthermore, it is unclear the extent to which moving beyond state borders affects the community's health seeking behavior. This is particularly relevant when having a state-specific health insurance, which can not be accessed in other states, such as the Chief Minister's Comprehensive Health Insurance Scheme. Additionally, language barriers may pose a significant issue for this semi-nomadic community while trying to access health care in another state, as the interviews show that the group speaks only Vagriboli and Tamil. While the Narikuravar's semi-nomadic character poses challenges on creating health policy and programs that would benefit them, it is also an opportunity to improve health promotion and delivery that transcends normal community boundaries.

#### **e. Alternative medicine use**

The Narikuravar are also renowned for their deep knowledge of natural-based healing practices and alternative medicine (Jackson 1989) They are oftentimes assumed to reject using allopathic

medicine and other forms of state provided health care because they prefer using traditional treatments. According to Mathur (2004):

The tribals who have been historically cut off from the basic facilities of human life such as health and illness, are left with the only alternative to reconcile with whatever is available to them within their cutoff region. In the past and relatively in the present situation also they meet the challenge of illness with the traditional system of disease management.

Therefore, the alternative, natural medicine system is particularly important for tribes, in the case of lack of access to modern care systems. During the study, some of the interviewed women reported using natural medicine and herbs to treat minor ailments, such as colds, headaches, and stomach aches, but some also reported using them in the case of emergencies like snake bites. Most of the women who use natural treatment buy the herbs from local stores, but a few collect them from the forest or grow them at home:

I have my own herbs plants at home. We use all these for various health issues. Like mudakathan for cold, vendhaiyam for heat and if we bitten by any venomous snake we use pepper to cure to poison. Neem can be used to reduce skin related issues. We use white egg and gingelly oil and apply in hair to reduce dandruff. We use to take herbal tea, using cinnamon, beacon, ginger, pepper, turmeric powder and jiggery. (Anuradha, 46)

I use to follow our traditional practices to treat, whenever children fall in sick due to diarrhea, heavy cold, fever and vomiting. Yes, it usually works. I use betel leaves, camphor, lemon, turmeric powder, garlic, ginger, vasambu. I get these from normal grocery shops, sometimes traditional medicine shops. (Chitra, 40)

While a lot of the women seem knowledgeable about herb properties in healing different ailments, such as Anuradha and Chitra, a surprising large number of women never uses natural medicine, namely 24 out of the 51 interviewed, although they are aware of its existence:

I don't use to follow our traditional practices. But I have heard people say it usually works. (Rekha, 29)

While alternative medicine seems to be well-known within the community, there is a positive attitude towards allopathic treatments, with a large number of women declaring they would much rather get treated in a hospital or clinic rather than self-treat using alternative medicine. This indicates that the community is interested in pursuing health care and access health care services, although it might not always be able to.

#### **f. Health awareness and use of public services**

To assess the effectiveness of the delivery of public health information to the Narikuravars, we surveyed community health behaviors such as getting vaccines for themselves and their children, accessing crèches and daycare centers, and being able to call a free ambulance. The results of health awareness driving health behaviors were mixed between the different types of programs offered for no cost by the government; however, the outreach of social and health workers to the community seemed effective.

Firstly, as vaccines are a public health priority of the Indian government, we surveyed vaccination behaviors. Out of the 51 women interviewed, 39 were vaccinated either during their childhood or during pregnancy. It is important to note that, given the age differences within our sample, the younger women tended to be more vaccinated during childhood, while older women

were either not vaccinated or vaccinated during pregnancy. However, generational results were positive, as only 3 women did not vaccinate their children. Therefore, a trend of better health awareness and behavior can be seen with the generational transition.

Government staff came and saw my children in my place. They informed us about vaccine and checked whether my children had vaccine. (Jaya Bharathi, 21)

Once they came and told about polio. They announced about vaccine and its importance. They told it will prevent 6 diseases from children but I don't remember what those are. (Radhika, 32)

We had vaccine in Sakkara Aalai. Hospital people came and gave vaccine. No one told us in person, we got to know by communicating with our community people. We didn't pay anything; it was given for free of cost. (Jayalalitha, 40)

While most women interviewed were informed about the importance of vaccination by social worker visits to their homes or by medical staff after their child delivery, it is important to not underestimate the power of in-network communication and information transmission, based on the strong internal ties of the community, such in the above-mentioned case of Jayalalitha. Moreover, the women report getting vaccines free of cost from local hospitals, so there is no additional direct financial impediment associated with vaccination, besides taking time off work. However, vaccine supply issues in hospitals were reported in some cases, making obtaining vaccines a lengthier process:

I went to government hospital to take vaccine for my child; however, they sent us back due to no medicine stock. Then I took my children to the mobile clinic which came nearby my place and had vaccine. I didn't pay any money for that. (Jaya Bharathi, 21)

Although a majority of women understood the importance of vaccination through the government workers' visits, the low level of education within the community, and perhaps the limited time available with health workers led to a majority of women not being aware of the vaccines they were administering their children, and not being able to recall the name of the vaccines when asked during the interview. In some cases, this may lead to an insufficient vaccination, an improper vaccinated timing, or the complete lack of vaccination of one's children:

I didn't have vaccine for any of my children. I didn't know more about it and no one told me about it. Moreover, my children born very healthy so I decided not to go for vaccine. (Jothilakshmi, 44)

However, the community also witnesses exceptions to the norm, through mothers who are informed about vaccines and their proper administration dates:

Yes, my children had vaccines from the 7th day of birth. For jaundice, polio, cholera, brain fever etc. 7th day of birth, 1 month, 1 and half month, 3rd month, 6th month. (Vasanthi, 39)

This further emphasizes how important strong community ties could be for transmitting health information, if health workers were to transmit easy-to-understand, proper information through well-connected individuals or community leaders. The women's role in obtaining vaccination for

their children is crucial, as they are the traditional care-taker. Their relatively higher level of sedentariness compared to the men in the community, especially when raising young children, makes them more easily reachable by health workers as well.

Besides vaccination, other health-care behaviors were learned through the visits of health workers. 36 out of the 51 women we interviewed were contacted by government officials regarding child monitoring and crèche services for their children, through the Integrated Child Development Scheme and Anganwadi Centers. These visits provide medical assistance and health check-ups for children, and distribute “healthy food like egg, health drink mix and some food”, free of cost. (Thangamani, 60) However, the semi-nomadic character of the community still poses impediments in accessing this type of information, despite having young children who would qualify for the free government services:

I don't get any information about the crèches because most of the time I am running for my bread and butter to nearby areas. So I don't get to know about such information.  
(Vanitha Ramesh, 35)

Moreover, an exceptionally high level of awareness was reported about the emergency service line 108, with the possibility of dispatching ambulances at no cost for the patient. 49 out of the 51 women interviewed knew about the existence of this service, while 23 used it. The service was mostly used during delivery, but also for other emergencies, and one woman remarked its efficiency: “they came immediately.” (Velakani, 20)

Finally, learning from experience, although painful, is another effective method through which the women from the community reported to have improved their health-seeking behaviors:



As seeing the consequence of the first baby lost I decided to take care of other children. Hence I continuously went to the checkup and had vaccination for me as well as my children. (Chithra, 40)

The community's subsequent openness to using health prevention and monitoring procedures provided by the government may signal a lack of opportunity to do so earlier, either through lack of information or lack of access to preventive and primary health care.

#### **g. Access to health insurance**

Most of the interviewed women were familiar with the concept of health insurance, although they weren't familiar with the term "insurance", which the interviewers oftentimes had to explain. Almost all women had a Family Card, or a ration card entitling poor families to welfare programs, and an Aadhar card, a biometric identification number; having these two cards allows families to access social services targeted for the poor, including health insurance. However, the number of families having health insurance was extremely low: only 20 out of 51 families reported to have health insurance, out of which 16 reported to have the Chief Minister's Comprehensive Health Insurance, the state-funded scheme. The utilization rates were surprisingly low: only 1 person reported to have used the Chief Minister's Comprehensive Insurance Scheme.

This reveals a plethora of systemic problems. Although the large majority of the Narikuravar population is under the poverty line, having a family income of less than Rs. 72,000 per year, and thus qualifies for free health insurance under the Chief Minister's Comprehensive Scheme, the reality on the ground is different. One of the core problem is the long waiting time for bureaucratic procedures, such as getting the Family Card, the Aadhar card, and the insurance

card once the application is processed. This is emphasized by the numerous staff with whom the community has to interact to obtain the health insurance, including the District Collectorate and the hospital health camp staff. This waiting time has been reported to be at least 8 months:

We have applied to it but still didn't get yet. Our community leader asked all of us to apply. So we did the same. It's been eight months still we didn't get any information for government side. (Nakma, 21)

I heard from people, I went and applied it but still didn't get the card, it's been eight months. (Bhavani, 27)

Additionally, there is a lack of information about the eligibility for the government-sponsored scheme, as well as about the ways to access it. The study has shown that a majority of women found out about the existence of the health insurance schemes through informal channels, such as neighbors and community leaders, and the information "reaches" them:

I got to know through others, public and neighbors. We got the insurance from government hospital in Virudhachalam. (Radhika Chandra, 27)

I do not remember how it came, but it reached us. (Radha, 36)

I do not know much about it... it is very difficult. We do not where to apply and whom to ask for. We applied it eight months before however we still didn't get it in hand. (Bhavani, 27)

However, it is the government's responsibility to disseminate information about the state-sponsored scheme to the eligible populations, either through social workers, government officials

or health workers. Moreover, it is the responsibility of the hospitals enrolled in the schemes to conduct health camps to register the population in the scheme. While this information might be disseminated through mass-media channels such as newspaper or TV, the lack of connectivity because of the low education level of the Narikuravar community might impede them from internalizing this information. Jayalalitha and Maarthal expand on their understanding of the root causes of this issue:

We didn't even know what it is until government say what it is. I don't know to read and write, so it's difficult for me to access any provision. As we are uneducated, it is responsibility of government to guide us on these and also let us know how to use the provision. However, no one does that so far, either government or private. No one educated us about this. (Jayalalitha, 40)

Similarly, Maarthal said:

I don't know whom I need to contact. As we people are not much educated, we don't know about most of the schemes provided by government. So education stands here as our first priority in order to know the details of all other public things as well... Actually I have seen about this in television but I never had one (Maarthal, 28)

The lack of education and connectivity with media and technology, and the lack of fulfillment of the government's responsibility to inform citizens about the state-sponsored health scheme are cited as the main issues for not accessing health insurance. Maarthal also highlights the issue of not knowing whom to contact in order to obtain insurance, which is a common trend among the women we interviewed, even if they may have heard about the existence of health schemes.

Additionally, even if the government attempts to inform Narikuravar citizens about their right to health insurance, their difficult daily lifestyle, marked by semi-nomadism and by being socially segregated because of stigma and poverty, may impede them from interacting with officials:

Government officials came to our community and conducted the awareness program in the center of the village but they didn't informed anything about it to people who lives in last street; I am also one among them. Several times I filled out the form and applied for it, but still we didn't get that. (Vijaya, 47)

This suggests that even within the Narikuravar community, there exists a hierarchy where the less poor who live a less nomadic lifestyle have more access to information from government workers, while those who may not have formal settlements and live on the street, like Vijaya, might be even more discriminated.

Obtaining an insurance card is not the only issue; utilizing it is even more problematic, as our study revealed a 5% utilization rate within the participant group. The low utilization is due again to the lack of education about the health insurance, its coverage and the main utilization procedures.

We have both cards but we never used it so far. We do not know how to use that and no one taught us about this. (Santha, 45)

Moreover, some providers in the region may choose to accept or reject the state-sponsored health insurance scheme, which gives them less revenue than a regular fee-for-service patient would pay. It is common for difficult situations to arise because of this; for example, patients using the

scheme might be sent from a hospital to another, thus wasting a lot of time in transit; or patients might get treated in a hospital that doesn't accept the insurance scheme, and later be charged by it. This confusion is worsened by the lack of clear rules, as Rajeswari explains:

I got the insurance but I was not able to use it in the government hospital because they said that it will be valid in the central government hospitals in each districts. So I didn't get any clear idea about the card and so I was not able to do this. (Rajeswari, 37)

This problem is amplified by the lack of information about the hospitals that accept a certain insurance scheme, or about the treatments covered by the scheme. The interviewed women had different opinions about what the health insurance does, oftentimes conflicting:

Yes, I heard about it but never accessed. I know that it will help in reduce medical charges especially to the poor people. They will reduce half medical charges through that card. (Anjali, 21)

We cannot use health insurance for minor health issues. Also it is not used for major problem also hence I personally feel health insurance is useless. (Meenakshi, 34)

The idea of having health insurance for only catastrophic health conditions is perhaps difficult to understand for the community, which struggles with concepts such as risk pooling and risk management, given their low education. They therefore view health insurance as “useless”, difficult to obtain, or impossible to understand and access, leading to both low coverage rates and low utilization rates.

Therefore, a number of issues arise in providing health insurance for the Narikuravars, even free of cost. The community's semi-nomadic lifestyle, low education levels and relatively

high illiteracy rates, together with the issues faced by the government in providing effective information about the access to and utilization of health insurance schemes, create a cycle of challenges for insuring this vulnerable community.

#### **h. Experiences in the allopathic medical system**

The Narikuravar community has a low rate of utilization of allopathic medical treatments, which it almost never frequents for chronic and non-urgent medical situations. According to the stories revealed by the interviewed women, their experience in allopathic facilities is mostly focused on tertiary care, while for primary and secondary care they tend to prefer self medicating with over-the-counter medicine or natural treatments. Radhika comments on the lack of health care utilization and on the need for a change in community behavior:

Yes. Our community people don't go for treatment and check up. So we need special doctors for our community alone. They need to check each and every part including kidney, uterus, lungs for everyone. Need special health assistance and attention for our community. (Radhika, 32)

Out of the interviewed women, 25 reported they used private hospital services for more serious medical conditions, while 21 chose public hospitals. One of the instances that the community deemed worthy of using allopathic treatment is during pregnancy and birth, as a majority of young women reported to have been to hospitals and to have sought medical attention and follow-up.

While the public system provides free care, which is important for the Narikuravar community given their poverty level, there was a large bias against utilizing it. The issues that were brought

up most frequently about the public system are the low quality and bad treatment that the community received. In once instance, a Narikuravar woman mentions that the doctors in public hospitals “do not treat people as human”. (Minima, 30) She expands on the degradation and lack of care she felt in the public sector:

I had very bad experience with government hospital that why I do not go to government hospital. I gave birth to my first child in private hospital without any trouble. [...] I went to government hospital for my second child delivery and really had worst experience. [...] They didn't give me any first aid; they didn't event touched me. I was screaming in pain but nurse and doctors were standing away and were cracking jokes. No one noticed me. I was really in horrible pain and was shouting but no one helped me. Later I took an auto and went to another hospital with pain. As soon as I reached another hospital I delivered the child. (Minima, 30)

Minima felt invisible and helpless, although she was shouting for help from the people whose job was to treat her. This experience built a bias against accessing the public system ever again, saying that she would rather prefer using the private system. Other women recall experiences of being argued with and humiliated, emphasizing the same bad quality of the medical staff:

I had undergone all the check up. One of the nurses told me that I have blood pressure. I informed the same to the doctor, he laughed at me and told me that I don't have blood pressure. Each one gave different responses. The doctor laughed at me and humiliated me. Government hospital response was really bad. Doctors and nurse will come and go in their own time during duty hours. They don't take care of us well and also don't treat us well. I got very bad experience in government hospital. (Jayalalitha, 40)

The lack of a consistent schedule, with medical staff choosing whether to come to work or not, signals a lack of oversight from the government, specific to public facilities. These inconsistent hours can pose an extra burden on the Narikuravar women, who may have to spend an unpredictably long amount of time in the hospital waiting for care. However, given their poverty level, seeking medical care instead of working might mean going without food for the day; these women cannot afford not to work, so they can only access public hospital in case of an actual emergency, rather than for more common illnesses.

Moreover, the added layer of expected bribery in public hospitals makes the care less affordable for the community, although it should be delivered for free. Jayalalitha's and Arukkani's experiences are indicative of the level of bribery and unfair financial charges for supposedly free care:

They kept asking money from us. [...] But hospital refused to discharge her and demanded for one more lac Rs. [Rs. 10,000]. I told the doctor about our economic situation that we can't pay furthermore, but they were so demanding on the money. (Jayalalitha, 40)

Doctors treated us very bad. They come very late and asked us to go for private hospital for treatment. They always ask money for everything, we have to bribe the ward boy, nurse, watchman, sweeper, everyone, to stay there. However, they don't give proper medicine and treatment. They discriminated badly by calling our community names and send us out. They asked money even in grave situation. We spent almost 30 to 40 thousand for these people. (Arukkani, 66)

Therefore, the combination of low quality of care, lack of attention paid by the physicians and nurses to the Narikuravar patients, the lack of available medicine and the "extra fees" charged



through bribery makes many Narikuravars prefer care in a private setting in case of emergency. The community reports good treatment and lack of discrimination in the private sector, because of the large out-of-pocket costs for the treatment:

I get good response from this private clinic, just because we are paying. We have been treated well and prescribed good medicine in private hospitals. But government hospital is worst in services; they treat us very badly, abuse us, humiliate us, and discriminate us. They are very careless in providing medicinal assistance. (Jayalalitha, 40)

My people do not go to government hospitals as they are discriminated by doctors and others badly. In government hospital, we often get treated very cheap so rather our people go to private hospital and ending up spending lot of money. (Velakani, 20)

The poor treatment they experienced in the public system drove Jayalalitha and Velakani to seek care in the private sector. The same considerations are common for women facing challenges in finding the money to pay for the private sector:

It's hard to spend money in private but I prefer to spend money in private rather getting treated badly in government hospital. (Minima, 30)

Therefore, a large part of the Narikuravar community prefers using private health services despite their high cost, which counterbalances the low quality of care in the public system. This may explain part of the reason why the community mainly accesses tertiary care, instead of primary or secondary care.

### **i. Health affordability**

The preference for private health system utilization that part of the Narikuravar community displays is accompanied by challenges in terms of health care costs. As previously discussed, the Narikuravars live in a very dire economic situation, and health shocks are oftentimes associated with pushing people into more poverty. In order to afford quality treatment in the private sector, many have to sell their assets, or borrow money:

We very well know that government hospital will not treat and give proper response. So we borrowed for interest from others and went to private hospital. They took care of me well. They gave injection and medicine on regular basis. (Radhika, 32)

Therefore, accessing health care is a financial burden, for which many Narikuravars choose to be in debt. However, others do not even have that choice, and choose to not get serious conditions treated because they cannot afford it:

My husband broke his leg in train accident. We spent more in private hospital but still [did] not recover. He is suffering in pain. But we couldn't take him to treatment as we don't have money for the treatment. (Siruvalli, 36)

Sometimes due to financial crisis I do not go. I go to pharmacy and take tablets for fever and head ache. (Nakma, 21)

As evidenced by Siruvalli's and Nakma's experiences, self-medicating and using natural, traditional treatments is a common alternative to treating illness in the hospitals for Narikuravar individuals who are not able to afford it. Moreover, even if they manage to pay for a certain procedure in the hospital, the follow-up proves to be financially difficult for most Narikuravars.

I was feeling very weak and anemic, I also lost weight and felt loss of appetite. I went to hospital and got medicine. They asked me to come for continued follow up but I didn't go due to economic condition. Because they charge 200 for fees and will write prescription for above 2000 Rs. which is difficult for me to afford it. [...] They gave medical prescription for 600 Rs. I paid it from my monthly salary.” (Bhavani, 27)

Like in the case of Bhavani, the added medical consultation fees and medicine costs add up to an amount of money that is impossible to pay from the small daily income of most Narikuravars. This emphasizes the importance of providing free or affordable quality care for the community through the private system, that will not drive families in debt; one of these methods is the Chief Minister's Comprehensive Health Insurance Scheme, for which the Narikuravar community is already eligible, but which it cannot access because of the afore-mentioned reasons.

#### **j. Narikuravar identity and discrimination**

The Narikuravar community faces a high level of stigma in the Indian and Tamil society. Their community is associated with being poor, dirty, uneducated, “gypsy”, and most people try not to touch them and stay away from them. This reputation also carries into the education system, where Narikuravar children are oftentimes met with violent actions and derogatory comments, and in the employment system, where there are no Narikuravars in any well-respected social positions:

No government job was given to any people in our community. Our community has been completely discriminated and kept away from all government provision. We have lot of graduated and educated people in our community, however not even a single person in government job. Government has not given any provision, facilities to our community.

They only come to us for calling vote in election times, after that they will always neglect our community from everything. Government has not taken any initiatives to develop our community. (Jayalalitha, 40)

Besides not having any Narikuravar representatives within the local government, our study revealed that there are no Narikuravar physicians or nurses present in the community. This poses the question of whether Narikuravars are discriminated during accessing health. When asked the question “how were you treated by doctors and medical staff” while seeking medical attention, the responses were polarized, negative or positive. Some of the women in the community immediately referred to the lack of discrimination within the medical system, despite that particular reference not being included in the question:

Was really treated well. They didn't show any discrimination. We went with new dress and we were so clean. Hence they treated us well. Even they changed our clothes. Helped us like God. (Nakma, 21)

Similarly, Radhika Chandra Sekar remarked:

Yes, I was taken care very well and I didn't face any caste discrimination. It was a good experience. (Radhika Chandra Sekar, 27)

The denial of injustice through depicting a very positive experience with discrimination is, however, common about vulnerable communities like the Narikuravars. The denial of injustice theory is supported by many claims of discriminatory practices faced in the health care system:

First Doctor didn't allow my husband for hospitalization just because we belong to this community. (Vashanti, 39)

I was treated badly, they didn't give proper injection, they gave injection only one in two days. I was treated badly by the doctors, they always be angry and scold me. By knowing that I belong to this community, he treated badly. They also didn't provide me [with] any assistance like Chief Minister ['s Health Insurance Scheme], kid kit, birth certificate. They asked me to go to other hospital. Later I went to other government hospital and got the provisions. (Radha, 36)

According to Vashanti and Radha, some of the discriminatory practices they faced were not being allowed access to health care, receiving bad treatment and being humiliated by the medical staff. Therefore, there is an additional layer of vulnerability that the community faces: besides not being able to access medical treatment because of the lack of education, lack of health insurance and the high out-of-pocket cost, the community oftentimes receives lower quality of care because of their cultural origin. Velakani explains the specific instances of stigma that the community faces when accessing care:

In hospitals, as soon as others see us they used to hold their nose as if we stink. They think we smell badly; we do not take bath like that. Even during work, people do not come nearby us. They stay away and buy things. They always humiliate us. Public used to threaten their children by saying they will hand over the children to us, as if we are dangerous or horrible people. Sometime I shouted back at them and asked them to treat us as normal human being. We have stigma that we are unclean people. (Velakani, 20)

Velakani touches on one of the main pre-conceptions that the community is facing: being dirty, which makes people stay away from them, and believe they are bad people. She explains that sometimes cleaning can be an issue for the community, given its semi-nomadic character:

But while travelling to other places we face challenges. We used to take our things along and travel to different places. We find place to do business and halt there. We can't move often from a particular place as it will be captured by others if we move from there. So it's hard for us to take bath and take care of ourselves. Still we used to keep our relatives there for some time and go and use public toilets. But most of the time we will not be allowed to public toilets. They will shout at us that we will not maintain clean. We will be blamed always if someone does dirty things. Even if we pay they do not allow us. We can't even use public toilet for emergency purpose. (Velakani, 20)

Therefore, since the community is always on the move and trying to work in order to survive, they have less access to sanitation than they would if they lived permanently in their settlements. However, the stigma of being unclean prohibits them from accessing sanitation and public toilets, creating a vicious cycle of discrimination. Velakani also discusses the generational change, as younger people entirely do not fit in the stereotypes, but they are still subject to the same misconceptions: "Generation changed, our people also developed a lot but still face discriminations. We are also human like others but public do not recognize us such." (Velakani, 20)

Finally, Narikuravars are stuck in a cycle of discrimination, in which their lack of power means that they cannot improve their situation.

I wanted to file a complaint on him and the hospital, but by considering our economic status, education and other I gave up. Because I know it is very hard for us to fight with these big people and get justice. [...] Our rights are getting denied always. we are being humiliated and discriminated by the government hospitals. (Jayalalitha, 40)

According to Jayalalitha's experience, although her family faced injustices while seeking medical treatment, there is nothing that she was able to do because of her low socio-economic status. Her experience also exposes a denial of discrimination at an institutional level, leading to an inability to bring such instances to justice. This leaves the Narikuravar community even more vulnerable and helpless, and at times discouraged that none of their efforts could change their situation where they face stigma and discrimination in every facet of their life.

## **IX. LIMITATIONS**

The study assessed the Narikuravar community in Tamil Nadu and its current health situation from a broad range of perspectives, including its socio-economic and educational status, nomadism, utilization of public health services, access to health insurance, experiences within the allopathic medical system, use of natural treatments, and vulnerability and discrimination within the health system. The perspective of the study is broad, as it is the first of its sort to address the intersection of different social factors with the access and utilization of health care. However, a more in depth analysis of each of these topics was not within the scope of the project, as the interviews were already particularly lengthy. A better understanding of these issues and their root causes would need to be based on a more in-depth future study, which we will attempt to develop in the future.

Moreover, we were limited in the number of interviews we were able to collect, due to limited human and financial resources, the long time length required, and challenging on-site logistics. While a sample of 51 makes the collected data relevant for analysis, a study

interviewing a larger proportion of the Narikuravar population would be able to quantify some of the qualitative assumptions we made in this paper.

## **X. SIGNIFICANCE AND RECOMMENDATIONS**

As the first study researching the healthcare-seeking behaviors and health access of the understudied community of Narikuravars in Tamil Nadu, the current paper can be used to broadly inform about the characteristics of the community and how they influence their health status. The study formalizes the information available about the Narikuravars, which was previously only based on oral transmission of information.

Firstly, the study can inform about some of the major causes influencing the access to health care of the Narikuravars. It is vital to understand the demographic and socio-cultural dimensions of access to health particular of marginalized groups, such as the Narikuravars, to create more equitable policy and welfare programs that will provide access to health for the most vulnerable groups in India. It is therefore important to further research, quantitatively and qualitatively, how dimensions such as gender, education, nomadism, discrimination and exclusion impact the experiences of Narikuravars in the health care system, and how it may be similar or different to other marginalized groups.

Secondly, there is a need for a better understanding of health care system design, in which marginalized groups, such as the Narikuravars, are sometimes excluded. Further research into policy design that would integrate nomadic or semi-nomadic populations into the health insurance system is needed. Moreover, the study can be supplemented by interviews with health



care providers, to better understand their perception of the discrimination and marginalization of the Narikuravar community through experienced interactions with the community. It is only by having a multilateral, complex understanding of the Narikuravars' experience in the healthcare system that their access to care can be improved.

## **XI. CONCLUSION**

The study researched and reflected upon a small, previously understudied group of people, to observe the intersection between education, gender, semi-nomadism, socio-economic status and discrimination, and its effect on preferences for care, health-seeking behavior and access to health care. It is meant as a start of a conversation about vulnerable, “Gypsy” communities’ access to health care, with a focus on the system in Tamil Nadu, India. It observes both challenges at an individual and community level regarding poverty, low education and discrimination, but also notices systemic issues of institutional discrimination. The study hopes to spring-board future research and a conversation about how to make health access more equitable, and provide this vulnerable group its right to health.

The paper also explores the community’s healthcare-seeking preferences, with a notable openness towards accessing allopathic treatment and biomedical facilities. The Narikuravar’s positive attitude towards accessing health contradicts the presumption that nomadic, “Gypsy” communities “are reluctant to seek help for health issues” as a main cause for their lack of appropriate access to health care (Sachdev 2012, 73). Moreover, the group’s socio-economic situation and low education levels leave it dependent on government initiatives and welfare, which sometimes do not reach the community although they should. Nakma explains her

experience waiting for government help during a flood that left the community without basic conditions necessary for health, such as sanitation and clean water:

We face hardship by having children and surviving in this environment. We do not have road, water facilities. [...] We do not have toilet facilities. A government official has not taken any initiatives. They only come here during election and ask for vote. We are suffering a lot without basic things like shelter, water, food. (Nakma 21)

The Narikuravar community's vulnerability and dependence on government services in order to maintain health make it imperative for a public policy shift, that can further analyze the structural reasons behind inadequate access to health care for the Narikuravars and design a plan to better integrate the community into the healthcare system and mitigate their discrimination. Only through structural changes on the basis of understanding the specific cultural context will India manage to provide health access more equitably, specifically to the bottom of the pyramid, or the most vulnerable of its populations.

*This research was performed in accordance with the Declaration of Helsinki and has been approved by Institutional Review Board, SUNY Oswego (application # 20150310db1). The thesis follows the draft article "Vulnerable Populations' Access to Health Care: A study of the nomadic "Gypsy" Narikuravars in Tamil Nadu, India" (Dragomir and Zafiu 2017).*

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